

December 4, 2014

The Office of Health Policy c/o Diona Mullins, Policy Advisor Cabinet for Health & Family Services 275 E. Main Street, 4W-E Frankfort, KY 40621



Hosparus Inc. ("Hosparus"), a Kentucky nonprofit corporation, has provided hospice care to 27 counties in Kentucky for nearly 40 years. While hospice is limited to individuals with terminal illness, there are a growing number of people who have complex or even terminal diagnoses that do not necessarily qualify for or desire hospice care. Hosparus Health, Inc., a supporting organization of Hosparus, formed GuidesCare Partners, Inc. d/b/a Care Guide Partners ("Care Guide Partners"), a Kentucky nonprofit corporation, to develop care models for individuals with chronic and advanced illnesses who need medical and psychosocial assistance in their homes but do not necessarily need the more acute care provided by private duty nursing or episodic care from home health agencies.

Care Guide Partners is very pleased with the intention of the cabinet to review and seek stakeholder input regarding the modernization of the certificate of need (CON) and the State Health Plan as outlined in the October 8, 2014 special memorandum. We appreciate the Cabinet for reviewing the existing framework and what improvements are potentially necessary to support the needs of an evolving health care delivery system and the goal of delivering the "Triple Aim" for Kentuckians. Furthermore, Care Guide Partners desires to deliver the Advanced Illness Management ("AIM") model of care in Kentucky in the very near future to fulfill our mission. The AIM model concurrently improves quality of life for the patient and family caregivers through reduced utilization of hospitals and other acute care services and overtreatment of illness while keeping patients in their homes and supporting their caregivers. These patients are identified through information provided by partner ACOs, Medicare Advantage plans, Medicaid managed care, and other health insurance organizations related to diagnosis, prior cost/utilization, and other factors.

The AIM model of care addresses the patient's needs across the continuum of care by integrating the patient's physicians, other healthcare providers, and case managers with an inhome, multidisciplinary team. A three-year pilot of At Home Support's AIM program with a large HMO in the state of Michigan generated significant cost savings in several key areas, including acute stays, ER visits, pharmacy and radiology, and resulting in a cost savings of 34% based on decreased utilization¹. In addition to cost outcomes, the program also produces exceptional patient and caregiver quality as well. Patient caregiver satisfaction scores consistently run 97% or higher. Care Guide Partners believes it can duplicate this success in the Commonwealth.



An aging population and rising end of life expenditures generate momentous challenges for the future of health care for Kentuckians. Chronic illness management during the last two years of life is a significant driver of why 5% of the U.S. population accounts for 50% of all healthcare spending². Caregivers suffer tremendous stress that can lead to illness and increased health care costs. Because home health and private duty nursing are not reaching a significant number of individuals battling chronic and advanced illness and hospice is often accessed in the last few days of life, if at all, the AIM care model is critical to bridging the gap in health care services today. It will provide the patient and caregiver with the education and resources necessary to manage symptoms and to prevent avoidable decline and overutilization of costly health care solutions.

Therefore, Care Guide Partners recommends the following to the Cabinet:

1. Allow longitudinal case management services as outlined under the AIM model within the existing CON and the State Health Plan requirements or make minor changes to accommodate this service.

2. Recognize the continuous evolution of payment models in the new value based framework of population health management and work to support providers exploring these models of care.

Sincerely:

Vice President

I LUP I.M

Phil Marshall President and CEO

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- 2. NIHCM Foundation Data Brief, July 2012, "The Concentration of Healthcare Spending"

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What is This?

Cost Analysis of a Novel Interdisciplinary Model for Advanced Illness Management

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Abstract

Purpose: This research project evaluated cost outcomes for patients in the @HOMe Support program, a novel interdisciplinary home-based program for patients and caregivers facing advanced illness drawing on the Chronic Care Model. **Methods:** Cost analysis involved paired sample t-tests to examine pre-post differences in health care expenditures obtained from Health Maintenance Organization (HMO) claims data for program participants. **Results:** Average 6-month costs per month significantly declined for patients older than 65 years of age from 1 HMO (US\$9300-US\$5900, P = .001). Evaluation of the second HMO showed that patients less than 65 years of age with lower preentry costs (<70 000) had a nonsignificant decline in total costs (US\$18 787-US\$13 781, P = .08). **Conclusions:** Study findings suggest @HOMe Support is associated with reductions in the use and cost for most health services over time.

Keywords

hospice, palliative care, chronic care, advanced illness management, caregiver, cost analysis

Introduction

It is critically important for health care providers and policy makers to address the needs of the growing number of persons with advanced incurable illness and their caregivers. Chronic disease accounts for 75% of all health care spending and studies suggest that 5% of all patients consume 50% of the costs. Patients with advanced chronic illness only comprise a 10% cohort of all those with chronic disease yet account for 64% of the total health care spending on chronic illness. ²

Besides the cost burden, there is untold suffering of this seriously ill population and their caregivers because current Medicare financial and reimbursement structures require patients and families to choose between aggressive, life-sustaining treatment and comfort-oriented hospice care. Relatively few patients with chronic disease with diagnoses such as heart failure and chronic obstructive pulmonary disease are referred for hospice services. Hospice is offered to those who have 6 months or less to live as determined by a physician. Furthermore, election of hospice is often viewed by physicians, patients, and families as giving up. The majority desire to try 1 more treatment despite the likelihood of limited success and often refuse hospice care if referred. The outcome of this brink of death care contributes to myriad suffering and escalating, unsustainable health care costs.

Although a variety of care models have been proposed for advanced illness, results to date have been inconclusive.

A randomized study of the Advance Illness Coordinated Care program in the Veterans Health Administration for persons with advanced cancer, congestive heart failure, and chronic obstructive pulmonary disease found no significant differences in costs between program participation and controls.9 However, a home-based palliative care intervention, compared to conventional care, garnered both increased satisfaction and decreased costs. 10 Patients receiving a palliative care, flexible benefits model increased their use of palliative services and had fewer acute care hospital days when compared to traditional hospice care. 11 To demonstrate the value of providing expanded choices for the millions of patients having serious chronic illness and relief to their burdened caregivers, additional studies are needed on usage patterns and costs associated with flexible advanced illness programs that do not require hospice election, limited life expectancy, or limitations on the use of curative treatments.

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The @HOMe Support program evolved from a pilot project based on the evaluation of a palliative care program for persons with advanced cancer. This palliative care program combined traditional hospice services with oncology care. A randomized trial evaluating program outcome was conducted for program participants compared with a group randomized to usual oncology care. Although no significant difference was noted in symptom control, there was a significant reduction in the decrease in quality of life (QOL) in the intervention arm. 12 Caregivers in the intervention group experienced a decrease in caregiver burden, measured by the Caregiver Burden Index at 1 month and 2 months following patient enrollment. 13 A small group of participants (n = 55) had complete data available for a comparative cost analysis of resource utilization and total cost of care between the palliative care program and the usual care oncology group. Findings indicated that intervention patients demonstrated substantial cost savings (US\$2540 per case in 2002) primarily from decreased emergency department visits, hospitalizations, and shorter hospital stays.12

The findings from the pilot oncology study described previously provided the framework and design of @HOMe Support. @HOMe Support was implemented in 2007 in collaboration with 2 large Health Maintenance Organizations (HMOs). Both HMOs identified a shared interest in improving access to supportive care while reducing costs for patients in the last year of life. One partnering HMO chose to target a younger population primarily with advanced stage cancer, while the other focused more broadly on both cancer and noncancer diagnoses, with the majority of patients older than 65 years of age. Many aspects of the program were measured, including types of services, costs associated with delivering the services, and frequencies of health care usage.

The @HOMe Support intervention is informed by the Chronic Care Model, ^{14,15} which suggests that functional and clinical outcomes for persons with chronic illness can be improved through productive interactions between patients and their health care teams. This improvement can occur through innovations in the organization of health care, as well as through advances in the larger social environment, including greater access to community resources and the development of health care practices and policies that encourage effective chronic disease management. The key components of this model are described subsequently.

Interdisciplinary Collaborations

Given the Chronic Care Model emphasis on organizing the care system to meet chronic care needs, the @HOMe Support program promotes sustained and ongoing collaboration among members of an interdisciplinary team. Interdisciplinary teams have demonstrated their value in many fields, including primary care, hospice, and palliative care, as well as in patient medical home models. The interdisciplinary team consists of nurses, counselors, personal care assistants, and volunteers. These groups develop collaborative treatment plans that focus on pain and symptom management, disease process education,

and goals-of-care discussions to support shared decision making. They also stress medication education and reconciliation, community referrals, health system navigation, and coordination among medical specialists.

Chronic Disease Management

The @HOMe Support program provides services to help chronically ill persons to better manage their diseases. Currently, services are determined by the patient's ability to carry out activities of daily living (ADLs), particularly when those services allow patients to remain independent and safe in their homes. Although the caregiver model emphasizes assistance in meeting ADLs needs of patient, it also includes screening for instrumental ADLs (IADLs) and developing specific interventions to address these needs. Health care practitioners use this model to collaborate with primary and specialty physicians to provide comprehensive and coordinated services.

Decision-Making Support

The @HOMe Support program focuses on promoting a partnership between patients and caregivers and health care providers associated with the program work to ensure that both patient and caregiver perspectives are considered. Determining patient preferences and facilitating treatment decisions require cooperation among all key players. Program staff support and advocate for those patients who make health care decisions on the basis of personal values and priorities that may or may not be in alignment with their family members. @HOMe Support program health care providers work to promote and facilitate completion of Durable Power of Attorney for Health Care documents when appropriate since research has shown that patients who have appointed a durable power of attorney for health care are less likely to die in a hospital or receive unwanted care. 20 Since studies suggest that health care surrogates sometimes make decisions in crisis situations based on their own values and preferences instead of the patient's medical condition or expressed wishes, @HOMe Support program staff work to ensure that caregivers fully understand the surrogate roles and responsibilities. 21,22

Caregiver Support

Consistent with the emphasis of the Chronic Care Model on providing support for the social environment, and recognizing the key role that caregivers play in this environment, caregiver support is a key component of the intervention. Caregiver support and training is based on motivational interviewing-based health coaching that has found to be an effective chronic care management intervention that focuses on supporting the role of caregiving. ²³

Following this model, @HOMe Support program staff coach caregivers to engage in effective communication and advocacy when working with health care providers and payers. Caregivers are also trained to promote safety in the home,

medication, and disease management and receive assistance with managing ADLs and IADLs.

Individualized Care

The @HOMe Support program provides patient-centered and individualized services as key components of effective and ethical care for persons with chronic conditions. 24 The duration of service provision depends on the patient's condition, identified needs, and trajectory of decline. Patients have the opportunity to discontinue services at any time. Although they are referred to hospice care when appropriate, patients and families who decide not to access these services may still receive palliative and comfort care from the @HOMe Support staff who are trained in these types of end-of-life care.

Methods

Study Setting

In 2010, the Maggie Allesce Center MAC of Hospice of Michigan, in collaboration with Wayne State University, secured a grant to rigorously measure cost outcomes. This study sought to provide critical information on the use and cost of services associated with a comprehensive advanced illness management program. The study was conducted in the Detroit metropolitan area. Case managers affiliated with 2 Detroit area health maintenance organizations (identified as plan A and plan B) as well as individual primary care providers, referred patients to the program. Services of the @HOMe Support Program were delivered by health care clinicians (physicians, nurses, social workers, and aides) affiliated with Hospice of Michigan, a large provider of hospice and advanced illness services in Michigan.

Study Design

The study design involves a retrospective analysis of data obtained from service records and from partnering HMOs. Data on demographic characteristics and services were collected from service records at Hospice of Michigan. Data on the use of inpatient, outpatient, home care, and emergency department services were obtained from HMOs where the patients were enrolled. Prior to data collection, we obtained data sharing agreements and administrative approvals from each partnering HMO. Study protocols were also approved through Wayne State University institutional review board and corresponding HMO internal research review boards. In order to protect confidentiality, partnering HMOs were provided a crosswalk file that listed names of @HOMe Support participants and a corresponding code number. The participating HMOs returned a deidentified data file that included health service use and cost variables for each patient. The crosswalk file was used to merge the data received from the HMO with @HOMe Support electronic medical record data containing @HOMe Support demographics and service use data. This deidentified data file was used for the analysis using SPSS version 19.1 software (IBM SPSS Statistics for Windows, Version 19.1, IBM Corp.).

Sample

The sample for this study included 148 patients receiving services from the @HOMe Support program between January 2007 and May 2011. Persons eligible for the @HOMe Support Program included HMO subscribers with advanced cancer, chronic obstructive pulmonary disease (Global Initiative for Chronic Obstructive Lung Disease stage III-IV and/or cor pulmonale), or congestive heart failure (New York Heart Association stage III-IV). Persons disabled by multiple conditions, including metabolic, neurologic, primary muscular diseases, and toxic disorders, were also eligible. These criteria are similar to hospice eligibility requirements. However, they do not include the requirement of limited prognosis, and there are no restrictions on the receipt of concurrent curative treatments.

Data Analysis

In order to analyze pre- and postcomparisons of service consumption and cost outcomes for program participants, we sorted all claims data by month, with a 13-month time line for each individual: 6 months preentry, entry month, and 6 months postentry month. The preentry period was defined as the 6-month period prior to program entry. The entry month was the 1-month period following program entry and the postentry period was the following 6-month period. To evaluate service consumption, claims were classified into 1 of the 4 categories of service: inpatient, outpatient, emergency, and home. To ensure comparability of costs across the span of the study, costs for each month were indexed to inflation. All costs were consumer price index adjusted to May 2011 dollars.

The data analysis proceeded in several steps. First, we used independent samples t-tests, with HMO plan type (A vs B) as the independent variable, to predict the use of @HOMe Support services. Separate t-tests were conducted to examine different aspects of service use, including length of stay and the total number of routine visits, on-call visits, phone visits, care coordination calls, skilled nursing services, health aid services. social work services, and the total number of services across all categories. Second, we used paired t-tests to compare the pre- versus postentry periods in terms of service use and costs. Separate paired t-tests were conducted for each service use and cost outcome, with time period (pre vs post) as the independent variable. The dependent variables included several different types of service use (inpatient, outpatient, emergency room, and home care services) as well as the associated cost outcomes for each of these service categories. Because we observed differences between plan A and plan B participants in terms of demographic characteristics and service use, separate analyses were conducted for participants in the 2 different plans. Finally, based on the results we obtained from the second step, we conducted additional analyses as a means of more fully exploring the dynamics of service use and costs among the @HOMe Support participants. For the plan A participants, this involved conducting separate analyses for 2 groups; those who died during the first 6 months of participation and those who survived

Table 1. Participant Demographic Characteristics (n = 148).

Characteristic	Plan B	Plan A	P Value*
Age at first admittance	53.03 (9.42)	69.01 (15.04)	<.001
Gender			
Male	41.5	57.8	.036
Female	58,5	42.2	
Race			
African American	15.4	23.2	.450
Caucasian	83.1	74.4	
Other	1.5	2.4	
Religion			
Protestant	50.8	56.4	.411
Catholic	27.9	29.5	
Agnostic/none	18.0	9.0	
Orthodox	1.6	3.8	
Muslim	0.0	1.3	
Jewish	1.6	0	
Cancer status			
Cancer	92.3	48.2	<.001
Not cancer	7.7	51.8	
Marital status			
Divorced	10.8	9.6	.003
Married	73.8	50,6	
Separated	4.6	2.4	
Widowed	3.1	25.3	
Unknown	7.7	12.0	
Caregiver type			
Spouse/partner	72.3	48.2	<.001 ^b
Adult child	9.2	37.3	
Other ^c	12.3	8.4	
No caregiver	6.2	2.4	
Paid professional	0	2	
Unknown	0	ī	

^{*}P value obtained from t-test (age at first admittance) and chi-square test (all other variables).

this period. For the plan B participants, we conducted separate analyses for those who had at least 1 high (>US\$70 000) postentry costs and those who did not incur these high costs.

Results

Study Population Characteristics

Demographic characteristics of persons in the intervention group receiving @HOMe Support services were separated by HMO (plan A vs plan B) in Table 1. We observed no differences in terms of race or religious categories by HMO status (P > .05). Plan A participants were older than plan B participants at the time of admission to the program (69.01 vs 53.03; P < .001) and were more likely than plan B participants to be male (57.8% vs 41.5%; P = .03). We observed significant differences in marital status (P = .003), with plan A participants more likely to be widowed (25.3% vs 3.1%) and less likely to be married (50.6% vs 73.8%) compared to plan B participants. Significant differences were also observed for

Table 2. @HOMe Support Service for Plan B and Plan A (n = 148).

Plan B. mean (SD)	Plan A, mean (SD)	Р
145.03 (231.28)	238.6 (269.00)	.007
51.32 (41.72)	92.67 (143.70)	.014
16.02 (18.70)	55.94 (110.98)	.002
0.78 (1.33)	0.98 (2.45)	.572
3.49 (5.03)	4.58 (6.72)	.279
9.35 (8.62)	,	.269
30.69 (25.82)	40.16 (46.91)	.121
3.89 (9.65)	30.82 (80.40)	.003
14.77 (16.62)	18.78 (24.67)	.262
	mean (SD) 145.03 (231.28) 51.32 (41.72) 16.02 (18.70) 0.78 (1.33) 3.49 (5.03) 9.35 (8.62) 30.69 (25.82) 3.89 (9.65)	mean (SD) mean (SD) 145.03 (231.28) 238.6 (269.00) 51.32 (41.72) 92.67 (143.70) 16.02 (18.70) 55.94 (110.98) 0.78 (1.33) 0.98 (2.45) 3.49 (5.03) 4.58 (6.72) 9.35 (8.62) 7.58 (10.39) 30.69 (25.82) 40.16 (46.91) 3.89 (9.65) 30.82 (80.40)

Abbreviation, SD, standard deviation.

caregiver status (P < .05), with adult child caregivers more common for plan A members, relative to plan B members (37.3% vs 9.2%), and spouse caregivers less common among plan B members compared with plan A (48.2% vs 72.3%).

The Use of @HOMe Support Services

@HOMe Support services used by intervention group members are shown in Table 2. Intervention group members in the plan A program had significantly longer lengths of stay compared to plan B members (238.60 vs 231.28; P = .007). The total number of @HOMe Support services was also significantly greater for plan A participants by comparison (92.67 vs 51.32; P = .014). Plan A participants had a significantly greater number of routine visits (55.94 vs 16.02; P = .002) and health-aide services (30.82 vs 3.89; P = .003) compared with plan B participants.

Declines in Health Care Use and Costs for Plan A and B Programs

Plan A participants. We observed decreases in emergency department services and costs; outpatient services and costs; and inpatient services and costs using a series of paired sample t-tests comparing pre- and postresults for plan A members. For the outpatient and inpatient categories, the observed differences between pre- and postentry were also statistically significant (P < .05). As shown in Figure 1, total costs per month declined USS3416 per month, from an average of USS9294 per month at baseline to US\$5878 at 6 months (P < .001). The percentage of plan A participants who experienced at least 1 hospitalization decreased from 83% in the 6 months preentry to 54% in the period following entry (P = .001). Mean hospital days declined from 7.65 in the 6 months preentry to 5.77 in the period following entry into the program (P = .027).

In a subsequent analysis, we stratified pre-post results by whether the patient had died at any time within 6 months after entering the program. The rationale for stratification was that

^bChl-square test was conducted on first 3 categories only (spouse/partner, adult child, and other) due to empty cells for some of the other categories.
Sincludes friend, niece/nephew, parent, or sibling.

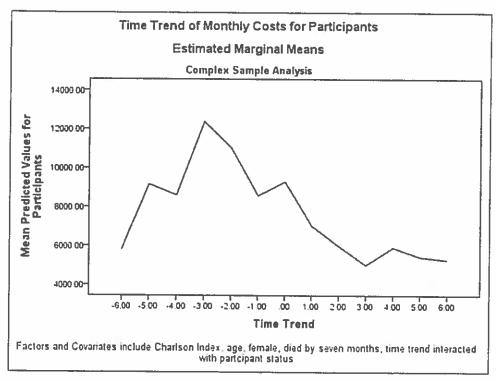


Figure 1. Plan A: trend of monthly costs for participants.

the program is designed to be more effective in terms of cost savings and improvements in QOL for patients within the last 12 months of life and not within relatively short time periods between program enrollment and death. For patients who survived at least 6 months postentry, the total average savings per month equaled US\$3829, a decline from an average of US\$8696 to US\$4867 per month ($P \le .001$). In contrast, for patients who died before the end of the 6-month period postentry, there was a nonsignificant decline of US\$2350 (US\$10835-US\$8485, $P \ge .05$). For those who survived at least 6 months, the percentage of hospitalized dropped from 84% to 54%. We also observed statistically significant reductions in the average number of days hospitalized in the pre- and postperiods for participants who survived for at least 6 months (6.6 vs 4.3 days; P = .008). Statistically insignificant declines were observed in the average days of hospitalization and the percentage of hospitalized for patients who had died within 6 months following entry.

Plan B participants. Since cost and the use of health care services typically increase in the last weeks of life, we completed separate analyses based on postentry costs. For plan B participants, costs differed substantially based on whether participants had at least 1-month postentry during which monthly costs exceeded US\$70 000. In contrast to the results for plan A, where only 3 members of the sample had such high costs postentry, 20.3% of plan B participants had at least 1-month postentry where total costs exceeded US\$70 000. These

participants had a very different pattern of service usage and associated monthly costs following entry than the 79.7% of the participants with lower monthly costs. For these reasons, the results are presented separately for these 2 groups, in the analysis subsequently.

- Participants where all monthly costs postentry <US\$ 70000.
- Participants where at least 1 monthly cost ≥US\$70000.

We compared pre- and postresults for plan B participants stratified by whether costs greater than US\$70 000 were observed at least 1 month postentry using a series of paired sample t-tests.

For the nearly 80% of the lower cost patients, average monthly outpatient costs declined from US\$6322 to US\$2849 (P=.001) and the number of outpatient services were reduced from 25.4 to 16.0 (P=.001). Although the differences did not reach conventional levels of statistical significance, the declines in mean inpatient costs and mean total costs was nevertheless substantial. Average inpatient costs decreased from US\$12 197 to US\$8786, while average total costs decreased by US\$5006 from US\$18 787 to US\$13 781. The proportion of patients with at least 1 hospitalization declined from 0.85 to 0.63 (P < .01).

In the high-cost subsample, statistically significant reductions in outpatient costs (US\$6415-US\$2385; P = .002) were accompanied by dramatic increases in inpatient costs (US\$14

156-US\$45 570; P=.003), leading to an overall increase in average total costs pre- and postentry from US\$20 845 to US\$51 435 (P=.004). There was a nonsignificant increase in the proportion of patients with at least 1 hospitalization, from 0.93 to 1.00 (P=.34). The plan B claims dataset did not include the number of days hospitalized.

Discussion

The @HOMe Support program provides an interdisciplinary, home-based program for persons with advanced illnesses and their caregivers. Based on the Chronic Care Model, the program focuses on disease management, symptom relief, health system navigation, shared goals of care decision making, and caregiver support. The present study examines service use and cost trends associated with that program as a means of informing future program development and intervention efforts.

The finding that cost reductions were observed among plan A subscribers surviving at least 6 months has important implications, confirming the value of early identification and enrollment before the onset of terminal decline. The large and significant increase in costs among those high-cost plan B patients suggests that the interventions came very late in the illness process. Future efforts should stress the earlier identification of potential high-cost users so that appropriate services and support can be provided in a more timely and efficient manner.

Study results indicate that home costs and services increased but were offset by substantially more reductions in the average costs. In all cases, the declines observed in number and costs of services were more substantial for those patients who survived for at least 6 months in the program. The small differences between pre- and postentry were not statistically significant for participants who died within the first 6 months. These results confirm the goal of the study to prove the value of earlier service enrollment.

Study results also indicate statistically significant declines in the average number of days hospitalized for plan A members who survived for at least 6 months. However, we also observed small but statistically nonsignificant reductions in the average days of hospitalization and the percentage of hospitalized for patients who had died within 6 months.

A primary limitation of this study is the use of administrative claims data for research purposes. The claims database provided by partnering HMO's lacked important variables such as the date of death, date of discharge to hospice, and others about illness severity, which are better predictors of death within a relatively short time frame. In some cases in which costs abruptly ended, there was no way to determine whether the cause was death, a change in coverage, or loss of coverage. The absence of these data made it impossible to define a comparison group. Including these variables into future prospective rather than retrospective studies would increase the probability that participants and comparison group members are similar on terminal-illness characteristics.

The lack of comprehensive outcome variables in claims data should also be considered and remedied structured in future studies. Data on hospital days were not available for the plan B sample, and we were unable to obtain comprehensive information about plan B hospice election. The inclusion of additional variables would also provide more comprehensive information on program outcomes. For example, given the emphasis placed by the @HOMe Support program on providing psychosocial support to improve QOL, the QOL indicators should be included for both the patients and their caregivers, so researchers could better ascertain QOL outcomes for both participants and comparison group members.

Conclusion

The rapidly growing number of adults living with serious chronic diseases, the emerging role of caregivers, and concerns with escalating costs of end-of-life care suggest the urgent need for the development and evaluation of programs such as @HOMe Support that provide care coordination and psychosocial support for patients and caregivers in this cohort.

This study challenges the current perception that adding home-based services contributes to escalating health care costs. Our findings suggest that a preventative, home-based strategy that adds services and benefit can lower total health care costs for participants. Development of appropriate comparison groups will strengthen this emerging model of advanced illness care.

The patient-caregiver dyad provides a unique opportunity for future research initiatives. The impact of a preventative caregiver model on the well-being and health care costs of family caregivers needs to be examined. Research into the unmet needs and the shared experience in illness management performed by family caregivers is limited, with the primary focus having been on the adverse effects that potentially need intervention, rather than examining the role prevention might play in support. 25,26 Athough there is a breadth of research on the adverse effects on caregivers, little is known about the role of a program such as @HOMe Support could potentially play in ameliorating caregiver anxiety, depression, strain, and mortality.

For institutions that provide coverage for patients and associated family members, further study of the potential benefits and additional cost savings in preventing the morbidity and mortality that have been shown to affect caregivers may prove beneficial. The potential preventative nature of @HOMe Support for caregivers will be a focus of further investigation. As the burdens of managing chronic conditions and providing end-of-life care continue to shift to family caregivers, novel models such as @HOMe Support will be increasingly necessary.

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THE CONCENTRATION OF HEALTH CARE SPENDING

NIHCM FOUNDATION DATA BRIEF JULY 2012



KEY POINTS FROM THIS BRIEF:

- Spending for health care services is highly concentrated among a small proportion of people with very high use. Conversely, a significant portion of the population has very low health care spending.
- People who are older or who have one or more chronic medical conditions or functional limitations are significantly more likely to be among the highest spending patients.
- High spending persists over multiple years for many patients, while others return to more normal spending levels after an expensive episode. There is also evidence that high spending occurs near the end of life for many patients, particularly within the Medicare population.
- Targeting the highest spenders represents the greatest opportunity to have a significant impact on overall spending, but implementation of strategies directed at high spenders is challenging for a number of reasons.
- The concentration of health spending also has important implications for health policies related to acceptance of and compensation for differential risks.

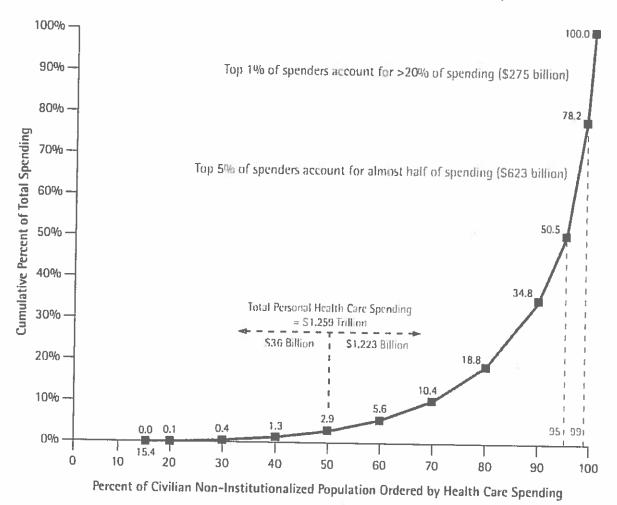
Spending for health care services in the United States is highly concentrated among a small proportion of people with very high use. For the overall civilian population living in the community, the latest data indicate that more than 20 percent of all personal health care spending in 2009 — or \$275 billion — was on behalf of just 1 percent of the population (Figure 1). The 5 percent of the population with the highest spending was responsible for nearly half of all spending. At the other end of the spectrum, 15 percent of the population recorded no spending whatsoever in the year, and the half of the population with the lowest spending accounted for just 3 percent of total spending.

Medicare claims data can be used to make similar calculations for the Medicare population specifically.

Those analyses show that spending is somewhat less concentrated for this population since individuals across the board are more likely to use health care services. Even there, however, recent data indicate that the top 1 percent of spenders account for 14 percent of

i These figures, derived from the Medical Expenditure Panel Survey (MEPS), exclude care provided to residents of institutions, such as long-term care facilities and penitentiaries, as well as care for military and other non-civilian members of the population. Likewise, they reflect spending only for personal health care services, not the much broader spending reflected in the National Health Expenditure Accounts (NHEA), which include government public health spending, administrative costs, research, capital investments and many other public and private programs such as School health and worksite wellness. As such, the total spending estimate from the MEPS (\$1.259 trillion in 2009) is significantly lower than the total spending reflected in the NHEA (\$2.496 trillion in 2009).

FIGURE 1. CUMULATIVE DISTRIBUTION OF PERSONAL HEALTH CARE SPENDING, 2009



NIHCM Foundation analysis of data from the 2009 Medical Expenditure Panel Survey.

program spending and the top 5 percent are responsible for 38 percent of spending.¹

With numbers like these, it is clear that per-person spending among the highest users is substantial and represents a natural starting point when thinking about how to curb health care spending. For instance, the average expenditure for each of the approximately 3 million people comprising the top 1 percent of spenders was more than \$90,000 in 2009 (Figure 2). The top 5 percent of spenders were responsible for

\$623 billion in expenditures or nearly \$41,000 per patient. In contrast, mean annual spending for the bottom half of distribution was just \$236 per person, totaling only \$36 billion for the entire group of more than 150 million people.

While the highly skewed distribution of spending has been observed for many years, spending has actually become slightly less concentrated over time as high spending has spread to a broader swath of the population. For example, whereas 56 percent of

\$100,000 Total spending by top 1% \$90,061 \$90,000 = \$275 billion. \$80,000 Mean Annual Expenditure Per Person \$70,000 \$60,000 Total spending by top 5% = \$623 billion \$50,000 Total spending by top 10% \$40,682 = \$821 billion \$40,000 \$30,000 \$26,767 Total spending by bottom 50% \$20,000 = \$36 billion \$12,265 \$10,000 \$7,980 \$236 \$0 Lowest 50% Top 50% Top 30% Top 10% Top 5% Top 1% 30.7M pop. 15.3M pop. 3.06M pop.

FIGURE 2. MEAN PER-CAPITA SPENDING BY SPENDING GROUP, 2009

Percent of Civilian Non-Institutionalized Population Ordered by Health Care Spending

NIHCM Foundation analysis of data from the 2009 Medical Expenditure Panel Survey.

spending was concentrated among the top 5 percent in 1987, this group accounted for just under half of spending in 2009. Similarly, the spending share for the top 1 percent fell from 28 percent in 1987 to about 22 percent in 2009. One explanation offered for this flattening of the distribution is the rise in population risk factors — most notably, obesity — and the corresponding increase in treated prevalence for chronic diseases linked to these risk factors, such as hypertension, diabetes and hyperlipidemia. That is, as more people are diagnosed with and treated for

these common chronic conditions, a larger share of the population will incur relatively high medical spending.

WHO ARE THE HIGH SPENDERS?

Analyses of the characteristics of people in the highest spending groups reveal few surprises. As would be expected, and consistent with earlier studies,^{2,4} data from 2009 reveal that the highest spenders are significantly older and in worse health. Although people

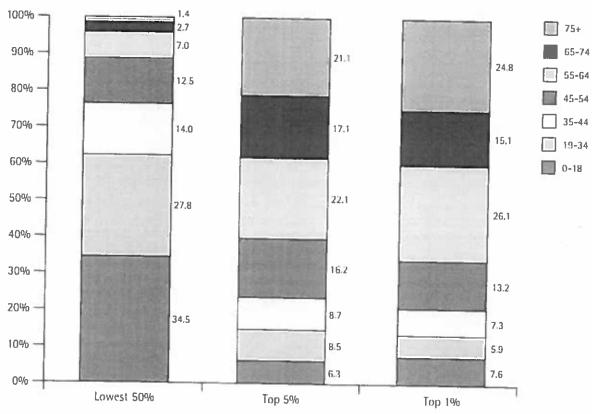
over age 64 comprise just 13 percent of the U.S. civilian population, they make up some 40 percent of those with the top 1 and top 5 percent highest spending (Figure 3). Conversely, 62 percent of those in the lower half of the spending distribution are under age 35, whereas this age group represents only 47 percent of the total population. The highest spenders also are significantly more likely to report that their health status is only fair or poor, while lower spenders overwhelmingly report very good or excellent health (Figure 4).

Additional insights on the relationship between health status and high spending come from a study conducted by the Lewin Group using MEPS data from 2006. They found that only 7 percent of people in the top 5 percent spending group reported having no chronic condition or functional limitation. Instead, roughly 30 percent of

these high spenders had at least one chronic condition but no functional limitation, another 30 percent had both a chronic condition and a functional limitation, and another 30 percent had chronic conditions and were so limited functionally that they needed assistance with one or more of the activities of daily living (Figure 5). Their work also demonstrated that the risk of being a high spender increased as the number of chronic conditions and functional limitations rose.

Data from the Lewin work can also be used to identify the specific chronic conditions often found among the highest spending patients. As shown in Figure 6, two-thirds of elderly patients with high spending had been diagnosed with hypertension, 45 percent had lipid disorders (high cholesterol), 37 percent had diabetes, and 30 percent had some type of unspecified

FIGURE 3. AGE DISTRIBUTION OF LOW VS. HIGH SPENDING GROUPS, 2009



HIHCM Foundation analysis of data from the 2009 Medical Expenditure Panel Survey.

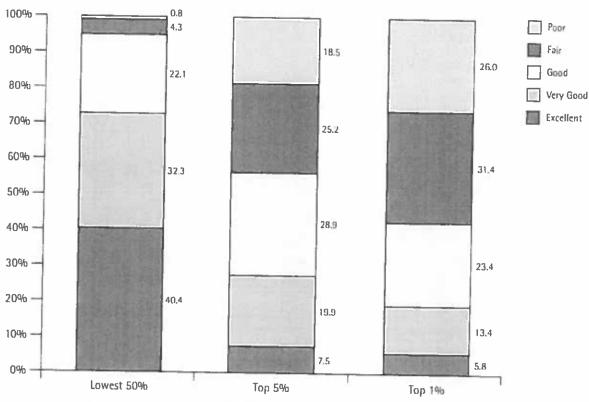


FIGURE 4. HEALTH STATUS OF LOW VS. HIGH SPENDING GROUPS, 2009

NIHCM Foundation analysis of data from the 2009 Medical Expenditure Panel Survey.

arthritis [arthropathies not elsewhere classified (NEC) or otherwise specified (NOS)]. Psychiatric disorders were also present for 15 to 19 percent of the elderly high spenders, as were heart-related conditions. Although prevalence rates for these conditions were uniformly higher among the very high spenders than among other elderly patients, several of the common conditions — notably hypertension, high cholesterol, and arthritis — were also relatively prevalent among elderly people who were not in the highest spending group, reducing the usefulness of these conditions for predicting high spending.

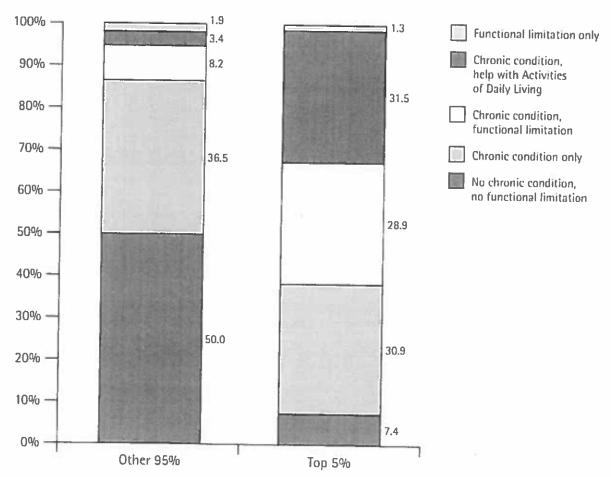
A similar analysis for high spenders under the age of 65 identifies many of the same conditions as being associated with high spending (Figure 7). Except for the psychiatric conditions, which were at least as prevalent for non-elderly high spenders as for their

elderly counterparts, the other conditions appeared less frequently among the non-elderly high spenders. When present, however, they were much more predictive of high spending. For example, while more than one-third of the non-elderly high spenders had high blood pressure, only 10 percent of those with lower spending had this condition.

THE PERSISTENCE OF HIGH SPENDING

Persistence Over Two Years. Because the Medical Expenditure Panel Survey follows sampled individuals for two years, we can use this source to examine the persistence of high spending over two years. Data from the 2008 – 2009 panel demonstrate that there is a fair degree of persistence in spending patterns (Figure 8), with only one-quarter of people moving between the

FIGURE 5. CHRONIC CONDITIONS AND FUNCTIONAL LIMITS AMONG LOW VS. HIGH SPENDING GROUPS, 2006



NHCM Foundation analysis of data contained in The Lewin Group, "Individuals Living in the Community with Chronic Conditions and Functional Limitations: A Closer Look," January 2013.

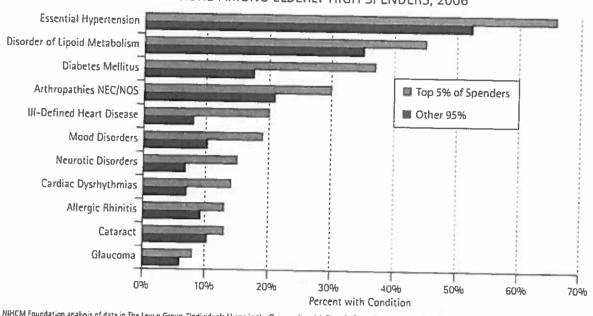
top and bottom halves of the spending distribution from year to year. Forty-five percent of those in the top decile of spending in 2008 and one in five of those in the very highest spending group remained in that group in the next year. Comparable analyses based on earlier panels document very similar patterns.

Figure 9 takes a closer look at the characteristics of people who remained high spenders vs. those who transitioned to a lower spending level after a year of high spending. Specifically, starting with the top decile of spenders in 2008, we compare the 45 percent who

remained in that group in 2009 with the 25 percent whose subsequent spending fell enough to classify them among the bottom 75 percent of spenders in 2009.

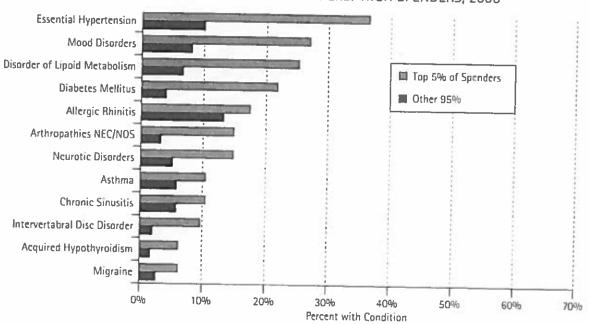
Clear and expected patterns emerge with respect to both age and health status. In the left-hand panel we see that those with persistently high spending were much more likely to be older, while those returning to lower spending in the second year were more predominantly younger patients. The right-hand panel considers the impact of health status. Health status information was collected from survey respondents around the end

FIGURE 6. COMMON CONDITIONS AMONG ELDERLY HIGH SPENDERS, 2006



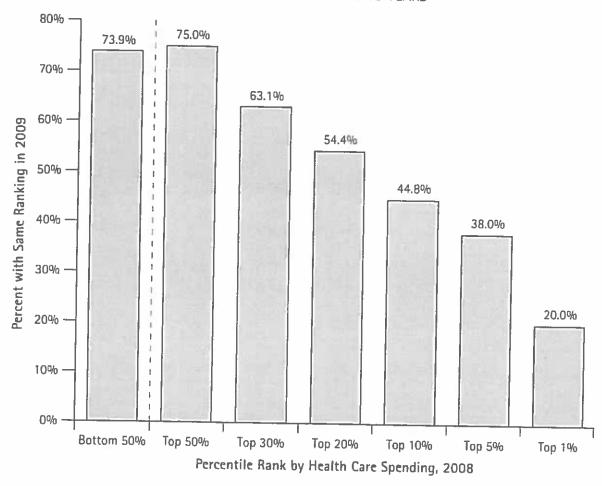
NIHCM Foundation analysis of data in The Lewin Group, "Individuals Living in the Community with Chronic Conditions and Functional Limitations: Closer Look," Jan. 2010. Featured conditions are among the most prevalent for both high and non-high spenders.

FIGURE 7. COMMON CONDITIONS AMONG NON-ELDERLY HIGH SPENDERS, 2006



NIHCM Foundation analysis of data in The Lewin Group, "Individuals Living in the Community with Chronic Conditions and Functional Limitations. Closer Look," Jan. 2010. Featured conditions are among the most prevalent for both high and non-high spenders.

FIGURE 8. PERSISTENCE IN SPENDING PATTERNS OVER TWO YEARS



Source: Cohen SB and Yu W. "The Concentration and Persistence in the Level of Health Expenditures over Time: Est mates for the U.S. Population, 2008-2009." Agency for Health Care Research and Quality, Statistical Brief #354. January 2012.

of 2008, that is, after they had already experienced a year of high spending but before they knew what 2009 would bring. While more than half of those who ended up remaining high spenders in 2009 had rated their health status as fair or poor at this mid-way point, more than half of those who experienced lower health spending in 2009 reported their health status as very good or excellent as that year was beginning. This finding points to the transitory nature of some health problems, even those that lead to very high spending for a period of time.

Persistence Over a Longer Period. An analysis by the Congressional Budget Office used Medicare claims data to examine spending patterns of Medicare beneficiaries over nine years. As shown in Figure 10, analysts began with the universe of Medicare beneficiaries who were in the top quartile of spending in 1997, and then examined the four-year periods before and after 1997 to see where these high spenders had been and where they ended up.

In each year prior to 1997, the high cost beneficiaries could have been either in the top quartile of FFS

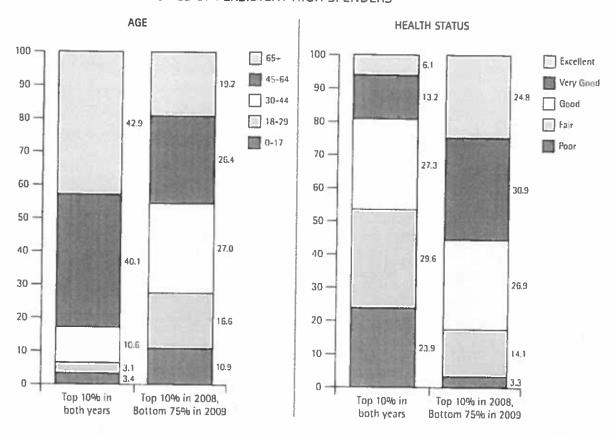


FIGURE 9. CHARACTERISTICS OF PERSISTENT HIGH SPENDERS

Source: Cohen SB and Yu W. "The Concentration and Persistence in the Level of Health Expenditures over Time. Estimates for the U.S. Population, 2008-2009." Agency for Healthcare Research and Quality, Statistical Brief #354, January 2012.

spending, in the bottom 75 percent, or not in FFS Medicare at the time (either because they were yet eligible for Medicare or, less likely, because they had a period of enrollment in Medicare managed care.) We see that nearly half of those who would be high cost in 1997 were also high cost in 1996 and more than one-quarter were high cost four years before. Similar patterns are observed when looking forward from the reference year: 44 percent of the high cost beneficiaries remained high cost in 1998, and one-quarter were high cost four years later. Although the same beneficiaries are not necessarily in the top 25 percent group in all years, as some might have had an expensive episode then returned to a lower level of spending, the data are very suggestive of persistent high spending that continues beyond the two-year period that can be

examined with the MEPS data. In fact, in a related analysis, C80 showed that half of all beneficiaries who were in the top quartile based on cumulative spending between 1997 and 2001 had high monthly costs for at least 22 of the 60 months in the period.

In addition to possibly transitioning to lower spending in the post-1997 period, high cost beneficiaries might also have died or moved out of FFS Medicare into managed care. The data show that 14 percent of the people who had high costs in 1997 died in that year and that 40 percent had died by 2001, revealing that a non-trivial portion of high spending within the Medicare program is for people in their final months or years of life. If we consider only surviving high-cost beneficiaries from 1997, nearly one-half also had high

costs four years later, again pointing to the long-term burden of living with chronic illnesses.

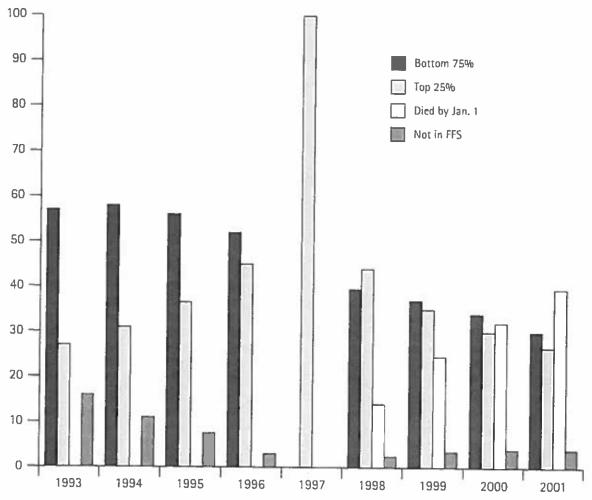
IMPLICATIONS OF CONCENTRATED SPENDING

The concentration of health care spending has several implications for health policy, particularly as we think about how to control overall spending for health services. First is the obvious need to "follow the money." With half of the population incurring just \$36 billion in health care costs, it simply is not possible to realize

significant contemporaneous or short-term savings by directing cost-control efforts at this group."

Strategies to improve management of chronic conditions, end-of-life care, and expensive episodes hold more promise, but raise challenges as well. To begin, accurate prospective identification of patients who can most benefit from disease management can be tricky since

FIGURE 10. LONG-TERM PATTERNS OF MEDICAL SPENDING



Source: Congressional Budget Office. "High-Cost Medicare Beneficiaries." May 2005.

ii Keeping this healthy population healthy, on the other hand, has the potential to lead to savings over the longer term by avoiding or delaying the onset of chronic diseases.

many of the same chronic conditions associated with higher spending are also present - and in the case of the elderly, highly prevalent - among lower-spending groups (Figure 6). Furthermore, even when these conditions are less prevalent for low spenders, the number of low spenders with the condition will be high simply because many more people are low spenders. Thus, interventions based solely on the presence of a chronic condition are bound to include a significant number of people who would not incur high costs, at least in the short term.7 Managing high spending at the end of life can also be problematic. Not all persons with high spending will die soon, and predicting timing of death and distinguishing between care that may extend life in a meaningful way and care that does little good is something that is often accomplished only in retrospect. Societal reluctance to discuss end-of-life care and fears of rationing only complicate the matter. Finally, although it might be possible to manage some of the expensive episodes more efficiently through use of clinical pathways, for example, it is virtually impossible to predict or avoid these random high-cost events.

A second implication of the highly concentrated spending pertains to the acceptance of risk by providers and payers. Emerging payment and delivery system reforms, such as accountable care organizations, rely on integrated provider organizations to accept some degree of risk for a defined patient population. These organizations will need a patient base that is large enough to balance out the sizeable downside risk of attracting just a few high spending cases. Additional risk-adjustment and other means of protection against high-cost outlier cases may also be needed. Similarly, in a world of community rating and guaranteed issue, insurers face a significant risk of adverse selection and negative financial implications if they happen to attract a disproportionate number of high spending patients. Here, too, adequate means of protecting against adverse selection and the risk posed by high spenders are required.

ENDNUTES

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ABOUT NIHOM FOUNDATION

The National Institute for Health Care Management Research and Educational Foundation is a non-profit organization whose mission is to promote improvement in health care access, management and quality.

ABOUT THIS BRIEF

This brief was prepared by Julie A. Schoenman, PhD, (jschoenman@nihcm.org), under the direction of Nancy Chockley, MBA, (nchockley@nihcm.org). We are grateful to Michael Hagan for his review of an earlier draft of this brief.

Part of the Foundation's larger research focus on health care spending, this document is the third in a series of briefs presenting current data and analysis on selected topics relevant to discussions of our nation's high and rising health care spending. The initial brief, "U.S. Health Care Spending: The Big Picture," provided an overview of health care spending in the United States and was followed by "Government Spending for Health Entitlement Programs."

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